Original Article

Changes in Distressing Behavior Perceived by Family of Persons with Schizophrenia at Home — 25 Years Later

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ABSTRACT

Background: Schizophrenia disorders as well as their symptoms cause distress to the family members or caregivers, which may cause poor quality of life. However, there have been advances in management, which could possibly alter this family distress. **Aims:** To determine if there was any change in the perception of distressful symptoms of schizophrenia, by the family members, now, 25 years after the initial studies in the same centre. **Materials and Methods:** Fifty-six consecutive and consenting new cases diagnosed as schizophrenia were administered the Scale for Assessment of Family Distress to identify the amount of distress caused by each of the symptoms reported. These findings were then compared with those reported by 50 patients, 25 years earlier. **Results:** Symptoms like does not do work and earn, does not sleep, and does not do household tasks were reported as the commonest distressing symptoms in both the samples, however, in the 1988 sample, negative symptoms like, slow in doing things, social withdrawal and has few leisure interests, were the commonest, in the present sample behavioral symptoms like beats and assaults others, threatens, is abusive and talks nonsense were the commonest distressing symptoms. **Conclusions:** The relatives of patients with schizophrenia suffer from considerable amount of distress and burden. There are some changes in the type of behaviours considered distressful in the current period. Assessing family distress is helpful in providing support to caregivers of persons with schizophrenia

Key words: *Expressed emotions, family distress, mental illness, QOL, schizophrenia*

INTRODUCTION

Family distress is the subjective experience of discomfort in the family members as a reaction to patients' behavior.[1,2] It can be conceptualized as an expression of psychological reaction, distress and dysfunction in family members arising out of the behavior and symptoms of the person with schizophrenia, independent of the caregiving role. Caring for patients with mental illness within the family setting is an important aspect of home based and community care of mentally ill. However, living with a person with severe mental illness cannot be considered very easy. The changes in behavior and personality of the patient can be very distressing for the close family members or the primary caregiver.[3] On the one hand, there is the difficult emotional adjustment in coming to terms with the disintegration in personality of a family member; on the other hand, the behavioral problems can prove extremely taxing to cope with. The distress is a function of various factors such as perception, knowledge, and

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attitude toward the mental illnesses. Studies since the 1960s have looked at the relationship between symptomatology of the patient and the distress/ burden experienced by the caregivers. Freeman and Simmons[4] observed that severe mental symptoms were most upsetting for the family members because the emergence of symptoms predicted rehospitalization. A significant degree of symptom tolerance was noted by Creer and Wing[5] albeit at a great deal of internal distress and family burden: Physical, emotional and financial. The commonest distressing behaviors noted were those related to social withdrawal and other negative symptoms. Research has tried to delineate the symptoms which are most distressing to the caregivers. A survey on families of patients with schizophrenia reported that offensive behavior, rudeness, and violence were most distressing.[6] Thus, the symptoms resulting from psychosis caused the greatest degree of distress whereas the negative symptoms evoked a sense of resignation. However, this finding was not corroborated in the study from India. Gopinath and Chaturvedi[2] while developing the Scale for Assessment of Family Distress (SAFD) in psychiatric patients reported that in patients with schizophrenia poor personal hygiene (58%) and wandering behavior were among the commonest distressing symptoms for the family members. Later, Gopinath and Chaturvedi[1] studied the distress of family members of patients with schizophrenia. The commonest behavioral disturbances found distressing were: Not doing any work (64%), not doing household tasks (56%), poor personal hygiene (53%), and slowness (53%). The symptoms considered most distressing were: Not doing any work (42%), few leisure interests (34%), talking less (29%), slowness (29%), and poor personal hygiene (29%). The lack of self-care was perceived as distressful more often in older patients and women. Caregivers were reported by Tennakoon *et al*.[7] to experience a high degree of worrying when the participants displayed difficult behavior and negative symptoms. Findings of the study by Gopinath and Chaturvedi[1,2] have been replicated by Saldanha *et al*.[8]

Boye *et al*.[9] prospectively examined the relationship between relatives' distress and patients' symptoms and behaviors, but no clear relationship emerged between PANSS total score and the relatives' distress. High levels of emotional distress and burden were observed by Ukpong[10] in the caregivers of schizophrenia patients in Nigeria which were significantly associated with positive and negative symptoms of schizophrenia. Family distress can be measured by generic scales measuring distress like the General Health Questionnaire or specific scales like the Scale for Assessment of Family Distress.[1,2]

The role of stigma in causing distress in family members was evaluated by Perlick and colleagues.[11] Women with schizophrenia and broken marriages are disabled and stigmatized not only by the illness, but also by the social attitudes to marital separation and divorce. Most families express intense distress and concerns about the long-term future and security of the women with schizophrenia.[12]

Studies of schizophrenia have found that coping by avoidance is associated with significantly greater distress and burden in caregivers and family members.[13-15] Coping through seeking emotional support, the use of religion/spirituality, active coping, acceptance, and positive reframing were associated with less distress, while coping through self-blame was associated with higher distress scores.[16] Greater self-reported family cohesion appeared to have a protective effect against emotional distress due to schizophrenia for family members of Latino and African American descent.[17] The family distress and the differential perception of distress for symptoms may be related to expressed emotions[18] and quality of life.[19,20] There are studies which report significant reduction in family burden by an intervention program and day care, without reducing family distress, due to lack of specific intervention to reduce family distress.[21] The relationship between the symptoms of the patients, distress due to the symptoms and the expressed emotions (EE) among the relatives is complex and a bidirectional relationship is likely to be the most valid one.[22]

The atypical antipsychotics were introduced in India in early 90s. There has also been a marked change in the economy, social systems and industrialization over the last two decades. There are some indications that the joint family system is gradually dwindling. In view of the speculated changes in the medications and changing lifestyle of Indian families, we were curious to know if there was any change in the perception of distressful symptoms of schizophrenia, by the family members, now, 25 years after our initial studies;, hence this study was carried out.

MATERIALS AND METHODS

Fifty-six consecutive and consenting new cases diagnosed as schizophrenia by International Classification of Diseases, Tenth Revision, ICD 10 (WHO) were included from the outpatient clinic. Patients with organic problems, alcoholism, drug dependence or mental retardation were excluded. A first-degree relative or spouse accompanying the patient was interviewed after good rapport was established. Data were recorded on a form designed specifically for this purpose. Informed consent was sought from the patients as

well as the relatives, and the study followed the ethical guidelines of the Institute. The interview form recorded details regarding: Identifying data of the patient; identifying data of the relative; demographic variables of patient and first-degree relative or spouse: Age, sex, education, occupation, habitat, marital status and family type; The key relative accompanying the patient was interviewed regarding the patient's behavior at home. They were then administered the Scale for Assessment of Family Distress[2] (See Appendix), which lists various behaviors that cause distress to the family members. Relatives were encouraged to mention as many behaviors as possible, irrespective of the amount of distress. Later, the relatives were asked to specify the amount of distress caused by each of the symptoms reported. Possible ways of handling such behaviors were discussed. The prevalence of various distressing symptoms was derived. The severity of distress was rated on a 5-point scale (0: No distress; 1: Minimal distress; 2: Moderate distress; 3: Marked distress; and 4: Intense or very severe distress). The severity was also assessed by asking the individuals to describe the distress in terms of percentage distress (from 0 to 100: 0-no distress, 100-maximum possible distress). This was easier, especially for rural patients. The severity was categorized for analysis as follows: No distress 0, Minimal distress 1-24, Moderate distress 25-49, Marked distress 50-74, and Intense distress 75-100.

The frequency of distressing behaviors noted in the present study was compared with the findings observed and reported in the earlier study[1] in this same Institute. Similarly, the frequency of severe distressing symptoms noted in the present study was compared with those reported in the study about two decades back.

RESULTS

There were caregivers or family members of 50 patients diagnosed as schizophrenia in the 1988 report, and 56 relatives of persons with schizophrenia in the 2012 study.

In the current study, the age of patients ranged from 18 to 61 years, mean 31.69 [SD 11.56], 21 males (45%), and 35 (55%) females, 40% were educated above SSLC and others were less educated, 54% were from an urban background. Half the cases were being looked after by their parents, who were interview for distressing behaviors; 18% sibs were interviewed, and spouses in 15%. Of the relatives interviewed for distressing symptoms, 40% were male and 60% females.

The behaviors which were as distressing in 2012 as in the 1988 report were - does not do work and earn, does not take care of himself, does not do household tasks, does not talk much, shows odd behavior/posture, is fearful, social withdrawal, has few leisure interests, and is slow in doing things. All other behaviors were considered significantly more distressful more often in the present sample of 2012 [Table 1].

On examining, the commonest distressing symptoms, interesting trends are observed [Table 2]. Does not do work and earn, does not sleep, and does not do household tasks were reported as the commonest distressing symptoms in both the samples, however, in the 1988 sample, negative symptoms like slow in doing things, social withdrawal and has few leisure interests, were the commonest, in the present sample behavioral symptoms like beats and assaults others, threatens, is abusive and talks nonsense were the commonest distressing symptoms.

Table 1: Frequency of distressing symptoms in 1988 study and current study

Behaviours distressing to family	1988	2012	*P* value
Does not do work and earn	40 (80)	46 (80)	0.778
Does not take care of himself	33 (66)	41 (73)	0.42
Does not sleep well	30 (60)	50 (89)	0.001
Does not do household tasks	34 (68)	47 (84)	0.054
Does not eat well	19 (38)	40 (71)	0.001
Does not talk much	26 (52)	39 (69)	0.063
Wanders away from house	13 (26)	35 (63)	0.001
Beats and assaults others, threatens	17 (34)	44 (79)	0.001
Tears clothes	4 (8)	23 (41)	0.001
Breaks household articles	3 (6)	35 (63)	0.001
Talks nonsense	18 (36)	44 (79)	0.001
Is Abusive	12 (24)	42 (75)	0.001
Shows odd behavior, posture	24 (48)	32 (57)	0.347
Is always suspicious	19 (38)	37 (66)	0.004
Attempted suicide	8 (16)	30 (53)	0.001
Is fearful	25 (50)	37 (66)	0.094
Social withdrawal	29 (58)	40 (71)	0.148
Has few leisure interests	30 (60)	38 (68)	0.423
Is slow in doing things	33 (66)	39 (69)	0.688
Is overactive	5 (10)	31 (55)	0.001
Gets and/or talks about odd ideas	13 (26)	37 (66)	0.001
Feels and reports sadness, depression	22 (44)	44 (79)	0.003
Shows socially embarrassing behaviour	9 (18)	34 (62)	0.001
Shows sexually embarrassing behaviour	5 (10)	19 (34)	0.003
Has incontinence	3 (6)	14 (25)	0.008
Any other behaviour	na	24 (43)	Na

Table 2: Percentage frequency of the commonest distressing symptoms, then and now

Commonest distressing in 1988	Commonest distressing in 2012
Does not do work and earn 80	Does not sleep well 89
Does not do household tasks 66	Does not do household tasks 84
Is slow in doing things	Does not do work and earn 80
Does not sleep well 60	Beats and assaults others, threatens 79
Has few leisure interests 60	Talks nonsense 79
Social withdrawal 58	Is Abusive 75

DISCUSSION

Most symptoms are perceived as distressful in the current sample as compared to the one of 1988. This is surprising as the current psychotropic agents are considered more effective and the families should have been more comfortable. The increased distress toward certain symptoms like abusiveness, and assaultiveness, are due perhaps to rising intolerance of the caregivers. The social structure of the families has got altered, with fewer joint families and fewer numbers of family members living together. More than 20 years back, negative symptoms and social withdrawal were considered more distressing as compared to positive and aggressive symptoms. In the current sample, this observation is reversed. The aggressive behaviors could possibly be causing difficulties in the household and community for the caregivers.

The implications of these findings are in planning services for the patients and the caregivers. Counseling on how to deal with aggressive behavior and use of appropriate medications to control such behaviors would be necessary.

There are no similar comparative studies, which makes it further difficult to understand and explain the observations. In a way, it implies that, some symptoms perceived as distressing by families 2 decades earlier, are still considered as distressful. There is no change in the outlook toward symptoms of psychosis. Since the present study was conducted after the introduction of atypical antipsychotics, one would have expected better tolerance of negative symptoms by the family members; but it is not so.

These observations perhaps contradict the findings of IPSS studies that the tolerance of psychosis has remained steadily good in developing countries. Interestingly, it has been noted that family distress scores correlate with other outcome measures for schizophrenia and affective disorders.[23] This might be related to the outcome of schizophrenia and its differences from developed countries. Quality of life (QOL) as an outcome measure has also been evaluated in patients with schizophrenia and its relationship with family distress in some studies has been reported.[20] Poor quality of life in patients was found to be related to high family distress. Poor QOL was also noted for those patients with negative symptoms, bizarre behavior, and formal thought disorder, symptoms which produce more family distress.[19]

Assessing family distress is helpful in providing support to caregivers of persons with psychosis. The role of family distress in contributing to expressed emotions has been proposed.[3,19] The scale for assessment of family distress (see appendix) has been useful in eliciting the behaviors perceived by family as distressing not only for schizophrenia, but also for alcoholism.[24]

CONCLUSION

The relatives of patients with mental illnesses suffer from considerable amount of distress and burden. Such relatives have been found to have greater degree of expressed emotion toward their mentally ill family member. The distress, burden and expressed emotions in the family members are significantly related to the outcome of treatment in psychiatric patients. Recent studies on psychoeducation of family members have documented its beneficial effect on outcome of psychiatric disorders. However, concerted efforts are required to overcome the barriers to care of psychiatric patients and their relatives in order to fulfill the mental health needs of the population.

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APPENDIX

SCALE FOR ASSESSMENT OF FAMILY DISTRESS
Gopinath and Chaturvedi, 1986;
Scale for the measurement of distress caused by symptoms to the family members.

Instructions: (Self administered or observer rated)

Following are various common disturbances which the patient can cause to you, by his behavior when at home. Please indicate whether these occur and if so which are the features which cause maximal distress to you, and how much? Consider the maximum possible distress as 4 and no distress as 0 and try to mark how distressful are the behaviors.

Criteria for severity of distress:

0 - No distress;
1 - Mild: Causing some amount of distress, occasionally
2 - Moderate: Some amount of distress frequently occurring or considerable distress occurring occasionally;
3 - Severe: Severe distress occurring frequently
4 - Profound or Very Intense: Too much distress occurring continuously

BEHAVIOURAL ITEMS	AMOUNT OF DISTRESS (0-4)				
	0	1	2	3	4
Does not do work and earn					
Does not take care of himself					
Does not sleep well					
Does not do household tasks					
Does not eat well					
Does not talk much					
Wanders away from house					
Beats and assaults others, threatens					
Tears clothes					
Breaks household articles					
Talks nonsense					
Is Abusive					
Shows odd behavior, posture					
Is always suspicious					
Attempted suicide					
Is fearful					
Social withdrawal					
Has few leisure interests					
Is slow in doing things					
Is overactive					
Gets and/or talks about odd ideas					
Feels and reports sadness, depression					
Shows socially embarrassing behavior					
Shows sexually embarrassing behavior					
Has incontinence					
Any other behavior					